

Pollicino (Tom-Thumb) Project: rare disorders patients finding their way



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ABSTRACT

BACKGROUND

METHODS

RESULTS_CONCLUSIONS

TITLE:
Pollicino (Tom-Thumb) Project: rare disorders patients finding their way

BACKGROUND:
In Italy, patients with rare disorders and their relatives lack good-quality information concerning the pathology they are affected by. Also in Europe patients complain about the scarcity of information. In relation to this, findings from the Eurodis Survey highlight the dilemma of rare diseases: lack of information, lack of appropriate medical training, difficulties in accessing care, and as a result, loss of confidence of patients in the health care system and the medical profession. The Veneto Rare diseases Register call centre - born in 2002 and contacted by 2000 users per year - focuses on the true needs of patients. Patients ask for different typology of information such as: the costs exemption they are entitled to have, the best reference centres they can refer to (what they are and where they are), pharmacological therapy - in terms of drug availability, distribution, accessibility of medical/pharmaceutical treatment in other Countries - assistance in paper work related to their pathology; rare disease diagnosis and follow up; contact person and location of patients associations; job rights and applications for civil invalidity. Through the activity of the Veneto Rare Diseases Register call centre, the affected patients and their relatives as well as professionals in the field are provided with comprehensive information on each specific pathology, ranging from medical factors to social and daily living aspects. Despite the richness of Italian web-sites in the arena, there is a need of a web-site answering all the different questions a patient might have, able to include all the dimensions of daily activities carried out by the patients, as well as to orient the patient among the huge information that is available on the net.

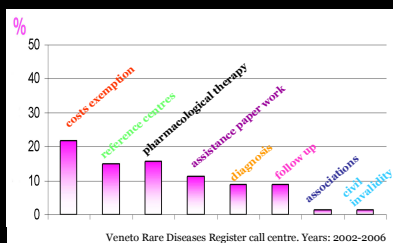
OBJECTIVE:
We aimed at planning, realizing and implementing a new web-site dedicated to patients with rare disorders, their relatives and health personnel. We aimed at re-organizing information already available on the net, making it more accessible to the users as well as adding new contents on specific patient's daily life aspects, through a knowledge transferability based on a peer-to-peer approach.

METHODS:
The project was organised in 3 sections.
1. gathering and re-organization of pre-existent information
2. realization of an information technology platform capable to support the organization of such contents
3. new information development on same daily living aspects of patients with rare disorders. A particular attention has been paid to patient advocacy, providing the patient with practical information on daily living aspects, i.e. school inclusion programmes, equal job opportunities, accessibility, leisure time, sports, etc. The web site has been developed as a search engine where you can search by disease or by patient macro-area (i.e. benefits the patients are entitled to get, schools). The information was obtained both from Public Institutions and from patients' associations. The information from the public institutions was based on medical description and health needs of rare disorders. The information from the associations web site, instead, was focused on healthcare aspects specifically originated from rare disorders and usually not covered by other web-sites in the field. The topics were organized in such a way that people who already had experienced a specific problem were given the opportunity to share their experience and to make it available to others.
The I.T. solution was chosen to offer this kind of information in a flexible and easy way and to guarantee the accessibility for patients with disabilities. A census of all web-sites in the field was made in order to find all the pre-existent information, whereas specific contents were developed through an ad hoc questionnaire. The questionnaire collected information on each specific association (name, foundation year, mission, services, activities, number of members) as well as on reference centres, national and regional laws, schools, transfers, best practises, leisure times, etc.

RESULTS_CONCLUSIONS:
Technically, the Pollicino web site was developed as a high technology search engine with a big informative flexibility. The web-site was built on different data bases to permit the separation of the various elements (Oracle data base and LDAP database); the platform Linux was chosen to guarantee security and stability standards of the system. A total of 34 associations, mostly belonging to the Uniarno Federation, participated in the project, filling in about 150 questionnaires. An analysis of the questionnaires, taking into consideration the Italian scenario on rare disorders, outlined the difficulty of getting useful and validated information. Even if available, such information is often dispersed across different sources and thus difficult to find. The needs expressed by the patients were: more information about national and regional laws; patients advocacy; more knowledge of rare pathologies provided by health professionals; difficulty availability of public transport-means and special structures such as schools, hotels and facilities for leisure activities.

In Italy, patients with rare disorders and their relatives **Lack Good-quality Information** concerning the pathology they are affected by. Also in Europe patients complain about the scarcity of information. In relation to this, findings from the Eurodis Survey highlight the **Dilemma of Rare Diseases**: **LACK OF INFORMATION**, lack of appropriate medical training, difficulties in accessing care, and as a result, loss of confidence of patients in the health care system and the medical profession.

WHAT KIND OF INFORMATION DOES THE PATIENT WANT?



Through the activity of the Veneto Rare Diseases Register call centre, the affected patients and their relatives as well as professionals in the field are provided with comprehensive **Information** on each specific pathology, ranging from **Medical Factors to Social and Daily Living Aspects**.

Despite the richness of Italian web-sites in the arena, there is a need of a **Web-site Answering All the Different Questions** a patient might have, able to include all the dimensions of daily activities carried out by the patients, as well as to **Orient the Patient Among the Huge Information That Is Available on the Net**.

We aimed at **planning, realizing and implementing a NEW WEB-SITE** dedicated to patients with rare disorders, their relatives and health personnel.

We aimed at **re-organizing information** already available on the net, making it more accessible to the users as well as adding **new contents on specific patient's daily life aspects**, through a knowledge transferability based on a peer-to-peer approach.

1. gathering and re-organization of **Pre-existent Information** and new information development on same daily living aspects of patients with rare disorders.

2. realization of an **Information Technology Platform** capable to support the organization of such contents

3. **New Information** construction

PRE-EXISTENT INFORMATION

A **CENSUS** of all web-sites in the field was made in order to find all the pre-existent information. The information was obtained both from **Public Institutions and from patients' associations**. The information from the public institutions was based on **medical description and health needs** of rare disorders. The information from the associations web site, instead, was focused on **healthcare aspects**.

IT SOLUTION

The I.T. solution was chosen to offer this kind of information in a flexible and easy way and to guarantee the accessibility for patients with disabilities: **WAI - WEB ACCESSIBILITY INITIATIVES (W3C: World Wide Web Consortium)**

NEW INFORMATION

The **QUESTIONNAIRE** collected new information on each specific association (name, foundation year, mission, services, activities, number of members) as well as on reference centres, national and regional laws, schools, transfers, best practises, leisure times, etc.

The **Pollicino (Tom-Thumb)** project has been carried out by **UNIAMO**, the Italian Alliance of patients' associations, funded by the **Ministry of the Social Solidarity**, and realized with the support of the Veneto Region Register for Rare Disorders

Pollicino **web site** was developed as a high technology **search engine** with a big informative flexibility

the web-site was built on **different data bases** to permit the separation of the various elements (Oracle data base and LDAP database)

the platform Linux was chosen to guarantee **security and stability** standards of the system

- A total of **34 associations**, mostly belonging to the Uniarno Federation, participated in the project - about **150 questionnaires** filled

An analysis of the questionnaires, taking into consideration the Italian scenario on rare disorders, outlined the difficulty of getting useful and **VALIDATED INFORMATION**

even if available, such **INFORMATION** is often **DISPERSED** across different sources and thus difficult to find

the **NEEDS** expressed by the patients were:
- more information about national and regional laws;
- patients advocacy;
- more knowledge of rare pathologies provided by health professionals;
- difficulty availability of public transport-means and special structures such as schools, hotels and facilities for leisure activities.

For additional information please contact:

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what is the information?
THE INFORMATION
is
to share patients experience
and to make it available to others

whose is the point of view?
THE POINT OF VIEW
is
the one of the patient